

Testimony of Heidi Williams

MS. WILLIAMS: Thank you.

Mr. Chairman, members of the committee, my name is Heidi Williams, and my children, Jayme, 8, and Jesse, 10, were recently victims of genetic discrimination. In August of 2003, I saw a commercial on television advertising affordable health care insurance for individuals through Humana, Inc. I called the toll-free number and talked with a young woman who quoted me a price for a policy that would cover both of my children. I was told that the monthly cost to insure my children would be approximately \$105, and I immediately told the young woman I would like to complete an application so that the coverage would begin as soon as possible.

I was asked a series of questions about my children, including whether or not they had a preexisting condition. I relayed to the young woman, under a threat of a fine and incarceration for falsifying information, the fact that my children were carriers of the genetic disorder called alpha-1 antitrypsin deficiency, or AAT, a liver deficiency that can progressively affect the lungs, the liver, or both, but that my children, unlike their mother, who is lung symptomatic, would never suffer from any aspect of the disorder.

The young woman, who wasn't quite sure what to do with this information, asked me to hold on the line while she contacted her supervisor. As I spoke with her supervisor, I again explained how my children were only carriers of the AAT gene and that my children themselves would never suffer from any aspect of the disorder as I am suffering, and that they are exceptionally healthy and active children. Again, I was told to hold the line because, as this gentleman was uncomfortable with the information I had imparted, he needed to contact his supervisor.

As I spoke to the senior supervisor, I once again relayed the information about alpha-1 and how my children were only carriers. To be born what is considered symptomatic, you must have two parents who are at least carriers of the AAT gene and be of a certain phenotype. I am what is considered the symptomatic phenotype of ZZ, and my husband is considered to be of a normal phenotype. Therefore, my children can only be carriers and, as research supports, will never be susceptible to the various problems symptomatic AATs face, including lung and liver failure.

Once the senior supervisor and I finished speaking, I was given back to the young woman who initially interviewed me and, after finalizing the application, was told by her that I would receive a reply to my children's application for health insurance within 24 hours. After five days of waiting, I knew instinctively that there had been a problem with my children's application. I received a letter two days later, exactly one week after the phone application, stating that my children were being rejected for their health care insurance through Humana, Inc., due to their AAT status and for no other reason.

After much self-recrimination, I shared my woes with the Alpha-1 Lungs and Life Chat Group, a large alpha-q Internet community that is extremely concerned about genetic discrimination, relating my frustrations and my fears for my children having been twice rejected for health insurance coverage. Nancye Buelow, who suffers from alpha-1 herself and was a representative of the Genetic Alliance at the time, heard about my problems with Humana, Inc. and approached me about publicly coming forward with my story through the auspices of the Genetic Alliance. I agreed, and together with the Genetic Alliance and the help of a prestigious Washington, D.C. law firm and a wonderful and very knowledgeable AAT doctor, an appeal to the August 2003 letter, a letter which rejected my children for health insurance coverage on the basis of their genetic status, was drafted and sent to Humana, Inc.

Enclosed within the letter to Humana, Inc. was research information from both the National Institutes of Health and the Alpha-1 Foundation supporting my argument that both Jesse and Jayme, as carriers, would not become symptomatic of alpha-1 antitrypsin deficiency and that both would remain free of AAT's debilitating destructiveness throughout their lifetime. In February of this year, I received my response to the written appeal and was once again shocked to read that my children were being rejected for health insurance coverage only on the basis of their AAT carrier status and nothing more.

It was only after Humana, Inc. had been approached by a reporter for a well-known and well respected newspaper that they reversed their decision and offered my children full coverage under their company prorated from August 2003 and paid in full until April 2004 by Humana, Inc. themselves. Fortunately for me, my children are now covered by a company that understands that everyone is entitled to affordable health care coverage, and not Humana, Inc.

Needless to say, Humana, Inc.'s reversal of their decision felt like a hollow victory. No one should have to force an insurance company to cover perfectly healthy children. In fact, I don't believe it should have mattered what their genetic status was to begin with. We are all viable members of a community with contributions to make and shouldn't have to be afraid that our genetic anomalies, in whatever form they arise, will be held against us. I should not have had to spend the better part of six months wondering if the decision to have my children's genetic status verified by their pediatrician was a huge mistake. I should not have to wonder if my children's genetic status is going to follow them into the workforce and render them unable to become employed in their chosen fields. And I certainly should not have to feel guilty for unknowingly passing this genetic anomaly on to my children.

Humana, Inc. made me feel guilty and ashamed for needing to know my children's genetic status. Furthermore, they made me feel guilty for needing a parent's peace of mind in regard to my children's future health, and for that I am angry. Today, there is a current of fear reverberating throughout the genetic community. It is not just a fear of loss, but it is a fear of retribution. It is a fear that forces many within this particular community to accept what should be unacceptable, discrimination by genetic status. Many people are afraid to come forward and fight for their rights to employment and health insurance coverage because they are afraid of the retribution that may not only be taken against them but could be taken against their families as well.

Therefore, it is because of the callous treatment of my children and the countless others before them that I want to make sure that this sort of policy practice never happens to anyone ever again. I want to make sure that I will never again exchange emails with someone who has been phased out of a position due to her genetic status. I never again want to hear the story of someone who has been denied health care coverage, had their health insurance coverage canceled, been passed over for promotion, demoted, fired, or simply not hired due to their genetic status.

National legislation that would make it illegal for insurance companies and employers to use someone's genetic status against them has indeed been drafted. The Senate passed S. 1053, the Genetic Information Nondiscrimination Act, unanimously last October, yet one year later this very important piece of legislation that would protect many Americans is still stranded in the House of Representatives. As each day passes and the genetic community waits for the House to bring this bill to a vote, scores of people across this nation are being persecuted on the basis of their genetic status. It is completely reprehensible that any type of discrimination still exists and has to be legislated against in this day and age. But since discrimination still exists, it must be swiftly eradicated in any form that it is found before its destructive force has had the chance to

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harm anyone else.

Finally, my family and I were extremely lucky. We had the backing of several people and organizations to help us fight our battle in the war against genetic discrimination that very few people in the genetic community win. Only through legislation and education will genetic discrimination loosen its hold on a community of people who are suffering from its devastating effects.

Thank you.

MS. MASNY: Thank you, Ms. Williams, for your very powerful testimony.